

From the Inside Out:

Dealing with TB-related
Self-stigma and Shame

A pilot toolkit for people with TB
to deal with self-stigma and shame

Handouts

Version 14: February 2019

About Beyond Stigma

Beyond Stigma (formerly known as The Work for Change) develops evidence-based programs to address feelings of self-stigma, worthlessness, and shame among vulnerable populations, primarily in emergent nations.

www.beyondstigma.org

About KNCV

KNCV Tuberculosis Foundation is an international non-profit organization dedicated to the fight against Tuberculosis (TB), the deadliest infectious disease in the world. This international center of TB control expertise promotes effective, efficient, innovative and sustainable TB control strategies in a national and international context. We are an organization of passionate TB professionals, including doctors, researchers, training experts, nurses, and epidemiologists.

www.kncv.tbcc.org

Modules 1 and 8

Baseline and endline questionnaire

Part 1: Van Rie Patient Perspectives Towards Tuberculosis

Question	Strongly disagree	Disagree	Slightly disagree	Not sure	Slightly agree	Agree	Strongly agree
I feel hurt by how others react to knowing that I have TB	1	2	3	4	5	6	7
I lose friends when I share with them that I have TB	1	2	3	4	5	6	7
I feel alone because I have TB	1	2	3	4	5	6	7
I keep my distance from others to avoid spreading TB germs	1	2	3	4	5	6	7
I am afraid to tell those outside my family that I have TB	1	2	3	4	5	6	7
I am afraid of going to TB clinics because other people may see me there	1	2	3	4	5	6	7

Question	Strongly disagree	Disagree	Slightly disagree	Not sure	Slightly agree	Agree	Strongly agree
I am afraid to tell others that I have TB because they may think that I also have AIDS	1	2	3	4	5	6	7
I feel guilty because my family has the burden of caring for me	1	2	3	4	5	6	7
I choose carefully who I tell about having TB	1	2	3	4	5	6	7
I feel guilty for getting TB because of my smoking, drinking, or other careless behaviours	1	2	3	4	5	6	7
Because I have TB, I am worried about also having AIDS	1	2	3	4	5	6	7
I am afraid to tell my family that I have TB	1	2	3	4	5	6	7

Part 2: Self-stigma knowledge and efficacy

Please choose one response to each question

Possible responses:

1 = Strongly disagree; 2 = Disagree; 3 = Slightly disagree; 4 = Not sure; 5 = Agree a little; 6 = Agree; 7 = Strongly Agree

I know what self-stigma is	① ② ③ ④ ⑤ ⑥ ⑦
I can give examples of the manifestations of self-stigma	① ② ③ ④ ⑤ ⑥ ⑦
Please give examples of the manifestations of self-stigma that you know	
I know the negative effects of self-stigma	① ② ③ ④ ⑤ ⑥ ⑦
I can give examples of the effects of self-stigma	① ② ③ ④ ⑤ ⑥ ⑦
Please give examples of the effects of self-stigma that you know	
I am equipped with techniques to overcome self-stigma	① ② ③ ④ ⑤ ⑥ ⑦
I can give examples of techniques to overcome self-stigma	① ② ③ ④ ⑤ ⑥ ⑦
Please give examples of the techniques that you know to overcome self-stigma	
I can assist other people who are experiencing self-stigma	① ② ③ ④ ⑤ ⑥ ⑦

Part 3: Self-compassion

Please choose one response to each question

Possible responses:

1 = Strongly disagree; 2 = Disagree; 3 = Not sure; 4 = Agree; 5 = Strongly Agree

When I fail at something important to me, I become consumed by feelings of inadequacy.	① ② ③ ④ ⑤
I try to be understanding and patient towards those aspects of my personality I don't like.	① ② ③ ④ ⑤
When something painful happens I try to take a balanced view of the situation.	① ② ③ ④ ⑤
When I'm feeling down, I tend to feel like most other people are probably happier than I am.	① ② ③ ④ ⑤
I try to see my failings as part of the human condition.	① ② ③ ④ ⑤
When I'm going through a very hard time, I give myself the caring and tenderness I need.	① ② ③ ④ ⑤
When something upsets me, I try to keep my emotions in balance.	① ② ③ ④ ⑤
When I fail at something that's important to me, I tend to feel alone in my failure.	① ② ③ ④ ⑤
When I'm feeling down I tend to obsess and fixate on everything that's wrong.	① ② ③ ④ ⑤
When I feel inadequate in some way, I try to remind myself that feelings of inadequacy are shared by most people.	① ② ③ ④ ⑤
I'm disapproving and judgmental about my own flaws and inadequacies.	① ② ③ ④ ⑤
I'm intolerant and impatient towards those aspects of my personality I don't like.	① ② ③ ④ ⑤

1) Self-stigma: what is it?

Self-disabling inner feelings of contamination, self-rejection, and self-loathing ... even when there is no objective reason to fear rejection or discrimination, and even when there is good objective reason to believe that they will receive external support, protection, treatment, and acceptance. *Justice Edwin Cameron (South Africa), 2012*

Self-learning tool 1:

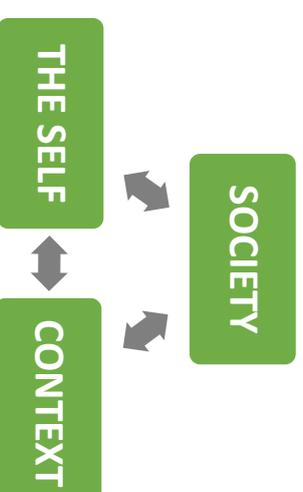
Understanding self-stigma

The key concepts

2) What does self-stigma cause?

- Not seeking care
- Higher levels of depression
- Fears around disclosure
- Lower quality of life
- Low self-esteem
- Reduced self-efficacy
- Lower treatment adherence

3) Self-stigma is the result of complex interactions between social, contextual and self factors



4) What does self-stigma look like?

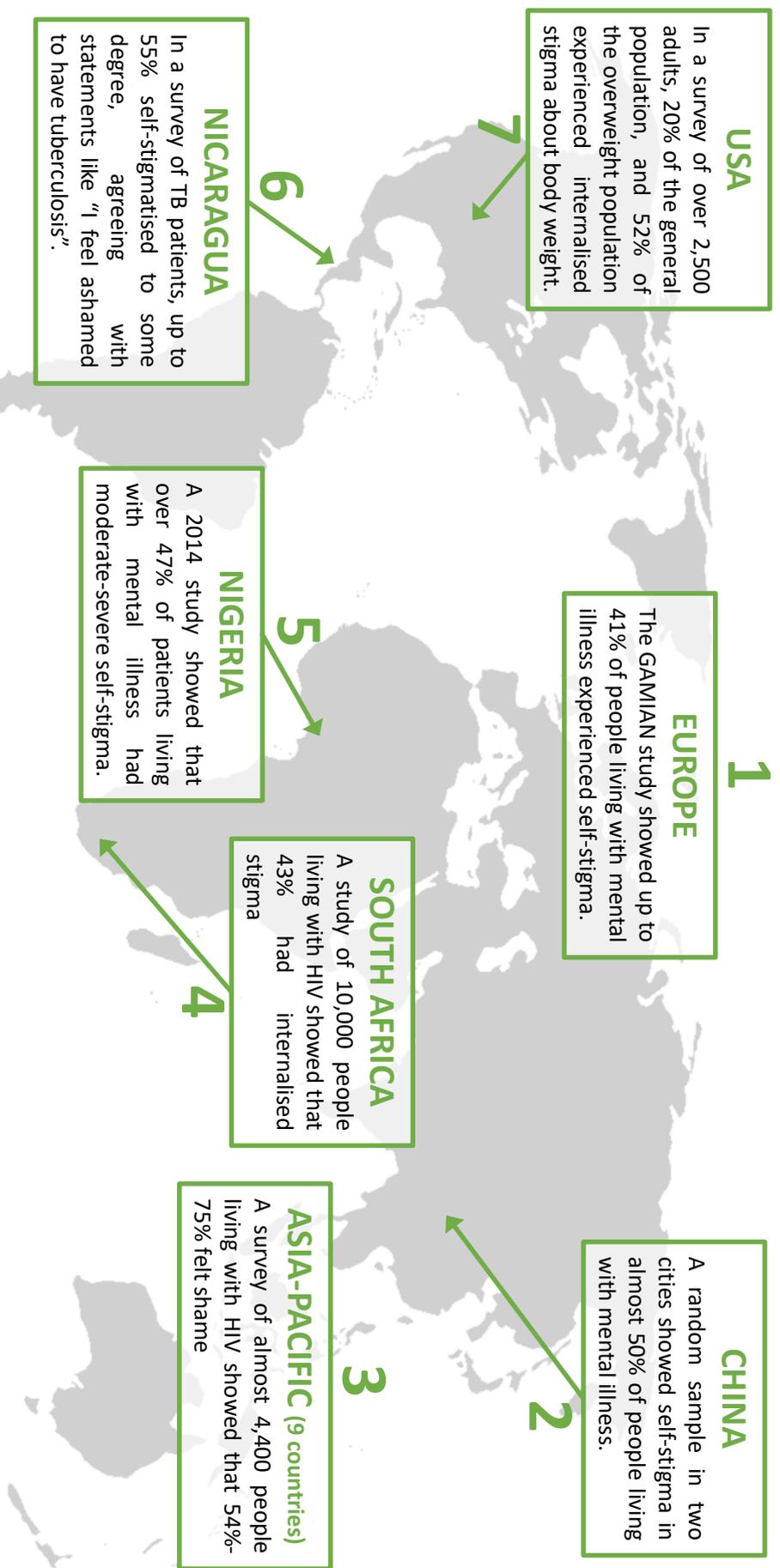
BELIEFS	FEELINGS	ACTIONS
<p>Stereotype endorsement</p> <p>"I believe TB is a sign of weakness"</p>	<p>Shame</p> <p>"I get embarrassed because of having TB"</p>	<p>Social withdrawal</p> <p>"I keep my distance from others because I have TB disease"</p>
<p>Self-blame</p> <p>Text</p> <p>"If I had taken better care of myself, I wouldn't have got TB"</p>	<p>Guilt</p> <p>"I can't forgive myself for exposing my family to TB"</p>	<p>Why try?</p> <p>"I won't go to school / work because I'm going to die anyway"</p>
<p>Self-agency</p> <p>"Having TB will affect my chances of keeping my job"</p>	<p>Perception of what others think</p> <p>"People will mistreat me because I have TB"</p>	<p>Negative coping</p> <p>"I don't go to the clinic because people will know I have TB"</p>

5) You don't have to be stigmatised to have self-stigma

- Negative beliefs in the community about a condition like TB, HIV, or mental illness can contribute to a person's self-stigma.
- Self-stigma includes internalised stigma. BUT an individual can already have self-stigma even if they've never actually been stigmatised.
- What I think you think about me is not always true. A person can self-stigmatise up to three times as much as others actually stigmatise them.

Self-learning tool 2: We are not alone!

Self-stigma examples from around the world



- 1) *Self-stigma, empowerment and perceived discrimination among people with schizophrenia in 14 European countries: The GAMIAN-Europe study.* Brohan et al. 2010
- 2) *The prevalence and predictors of self-stigma of individuals with mental health illness in two Chinese cities.* Young and Ng. 2016
- 3) *People Living with HIV Stigma Index: Asia Pacific Regional Analysis.* Global Network of People Living with HIV
- 4) *The People Living With HIV Stigma Index: South Africa.* South African National AIDS Council. 2014
- 5) *A comparative study of self stigma between HIV/AIDS and schizophrenia patients.* Oduguwa et al. 2014
- 6) *Tracking tuberculosis patients' internalized social stigma through patient centred care: An intervention study in rural Nicaragua.* Macq et al. 2008
- 7) *Internalizing Weight Stigma: Prevalence and Sociodemographic Considerations in US Adults.* Puhl et al. 2017

Exercise 1:3

Ryff Dimensions: questionnaire

ADAPTED RYFF STATEMENT	Strongly disagree	Disagree	Slightly disagree	Not sure	Slightly agree	Agree	Strongly agree	Summary Score
DIMENSION 1: AUTONOMY								
I am not afraid to say what I think, even if it is different from what others think.	1	2	3	4	5	6	7	
My decisions are not usually influenced by other people.	1	2	3	4	5	6	7	
*I worry about what other people think of me.	1	2	3	4	5	6	7	
*I am often influenced by people who have strong opinions.	1	2	3	4	5	6	7	
I have confidence in my opinions, even if they are different from everybody else's.	1	2	3	4	5	6	7	
*It is difficult for me to give my opinion on controversial subjects.	1	2	3	4	5	6	7	
I judge myself by what I think is important, not what other people think is important.	1	2	3	4	5	6	7	
DIMENSION 2: ENVIRONMENTAL MASTERY								
I feel like I am in control of my life.	1	2	3	4	5	6	7	

ADAPTED RYFF STATEMENT		Strongly disagree	Disagree	Slightly disagree	Not sure	Slightly agree	Agree	Strongly agree	Summary Score
*Everyday life often makes me feel sad.		1	2	3	4	5	6	7	
*I do not fit in very well with the people and the community around me.		1	2	3	4	5	6	7	
I am good at managing the responsibilities in my daily life.		1	2	3	4	5	6	7	
*I often feel like I cannot cope with my responsibilities.		1	2	3	4	5	6	7	
*It is hard for me to live in a way that I find satisfying.		1	2	3	4	5	6	7	
I like my home and my life.		1	2	3	4	5	6	7	
DIMENSION 3: PERSONAL GROWTH									
*I am not interested in doing new activities.		1	2	3	4	5	6	7	
It is important to have new experiences that change the way I think about myself and the world around me.		1	2	3	4	5	6	7	
*I do not think I have improved as a person over time.		1	2	3	4	5	6	7	
I think that I have developed a lot as a person over time.		1	2	3	4	5	6	7	
*I do not like being in new situations where I have to change my way of doing things.		1	2	3	4	5	6	7	
My life has been a continuous process of learning, changing, and growth.		1	2	3	4	5	6	7	
*I gave up trying to make big improvements or changes to my life a long time ago.		1	2	3	4	5	6	7	
DIMENSION 4: POSITIVE RELATIONSHIPS WITH OTHERS									
Most people think I am a loving and affectionate person.		1	2	3	4	5	6	7	
*It has been difficult and frustrating for me to maintain close relationships with other people.		1	2	3	4	5	6	7	
*I often feel lonely because I do not have many close friends to share my worries with.		1	2	3	4	5	6	7	
I enjoy talking closely with family and friends.		1	2	3	4	5	6	7	
Other people think I am generous, and that I am willing to share my time with them.		1	2	3	4	5	6	7	
*I have not experienced many good relationships with other people.		1	2	3	4	5	6	7	
I know that I can trust my friends, and they know they can trust me.		1	2	3	4	5	6	7	
DIMENSION 5: PURPOSE IN LIFE									
*I live life one day at a time, and don't really think about the future.		1	2	3	4	5	6	7	
I have a purpose in life.		1	2	3	4	5	6	7	
*I often feel like my daily activities are meaningless.		1	2	3	4	5	6	7	
*I do not know what I want to accomplish in my life.		1	2	3	4	5	6	7	

ADAPTED RYFF STATEMENT		Strongly disagree	Disagree	Slightly disagree	Not sure	Slightly agree	Agree	Strongly agree	Summary Score
	I enjoy making plans for the future and working to make them happen.	1	2	3	4	5	6	7	
	Some people do not have goals in their lives, but I am not like that.	1	2	3	4	5	6	7	
	*I sometimes feel as if I have done everything that can be done in life.	1	2	3	4	5	6	7	
DIMENSION 6: SELF-ACCEPTANCE									
	I am pleased with how my life is.	1	2	3	4	5	6	7	
	In general, I feel confident and positive about myself.	1	2	3	4	5	6	7	
	*I feel like many of the people I know have better lives than me.	1	2	3	4	5	6	7	
	I like my personality.	1	2	3	4	5	6	7	
	*I feel disappointed about my achievements in life.	1	2	3	4	5	6	7	
	*I feel less positive about myself than other people feel about themselves.	1	2	3	4	5	6	7	
	When I compare myself to the people I know, it makes me feel good about who I am.	1	2	3	4	5	6	7	

Exercise 1:3

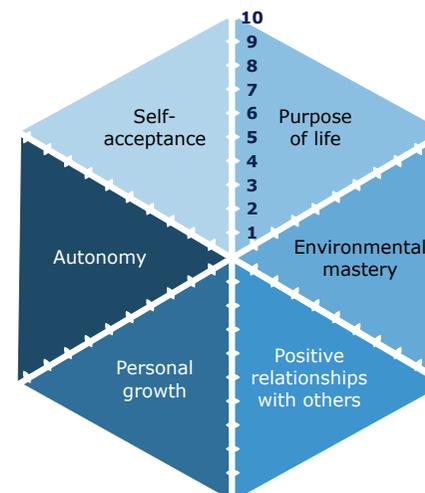
Ryff Dimensions: things to think about

RYFF DIMENSIONS

Figure 7.
Ryff Dimensions -
things to think about

Figure 6.
Ryff dimension scale chart
Adapted from: Ryff et al, 1995.[7]

- ▶ **Self-acceptance:** Does the person like their appearance / personality / life?
- ▶ **Purpose in life:** Does the individual have goals or things they want to achieve in their life?
- ▶ **Environmental mastery:** How well does the individual cope with their circumstances and environment? Do they feel like they are in control of their life?
- ▶ **Positive relationships with others:** Does the individual have meaningful and good relationships with other people?
- ▶ **Personal growth:** Is the individual growing and improving as their life progresses?
- ▶ **Autonomy:** Is the individual able to live and cope independently of others?

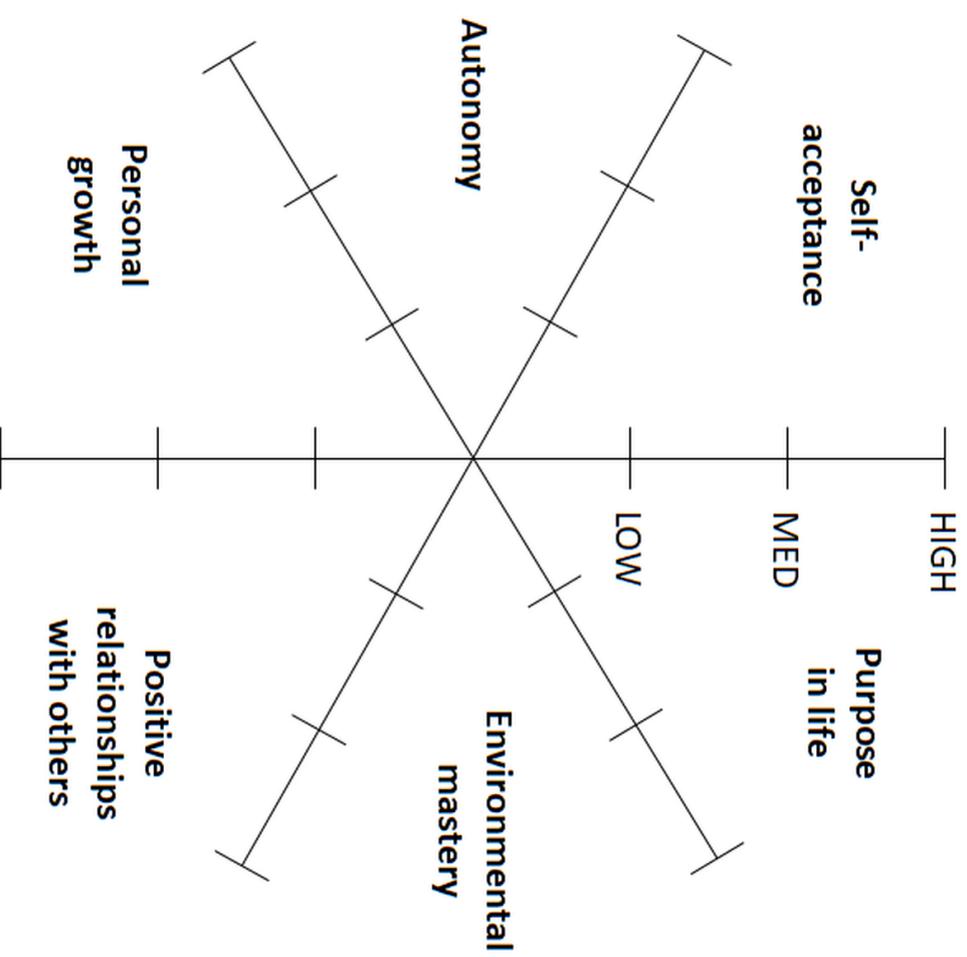


Ryff Dimensions - things to think about

DIMENSION 1: AUTONOMY	Are you often influenced by people who have strong opinions?	DIMENSION 4: POSITIVE RELATIONSHIPS WITH OTHERS	Do people think you are a loving and affectionate person?
	Do you have confidence in your own opinions, even if they are different from everybody else's?		Do other people think you are generous and willing to share your time with them?
	Do you judge yourself by what you think is important, not what other people think is important?		Have you experienced many good relationships with other people?
DIMENSION 2: ENVIRONMENTAL MASTERY	Do you feel like you are in control of your life?	DIMENSION 5: PURPOSE IN LIFE	Do you make plans for your future?
	Does everyday life often make you sad?		Do you have goals in life?
	Are you good at managing the responsibilities of your daily life?		Do you feel like you still have plenty to do in life?
DIMENSION 3: PERSONAL GROWTH	Do you think it is important to have new experiences that change the way you think about yourself and the world around you?	DIMENSION 6: SELF-ACCEPTANCE	Are you pleased with how your life is?
	Has your life been a continuous process of learning and growth?		In general, do you feel confident and positive about yourself?
	Do you sometimes like to make big improvements or changes to your life?		Do you feel like many of the people you know have better lives than you?

Exercise 1:3

Ryff Dimensions: blank chart



EXERCISE 2.1 - Keeping a TB Journal



My TB journal template

This is my journal on:

Write today's date here

This is me, as I am today



Today I am feeling...

Describe how you feel, and what that means for you



What is on my mind today?

Write everything that is going on in your head

These are my negative thoughts



What negative thoughts have I had about TB today?

Write whatever negative thoughts arise



How does that make me feel?

Describe any emotions and feelings you have

Have I felt shame/self-stigma about TB today? If so, in what ways and how did I feel?

Write any experiences of self-stigma and shame you can identify



What would my closest family member or friend say to me today?

These things were good today



Three things I am grateful for today:

Write ANYTHING you are grateful for, big or small



What am I proud of doing today?

Write ANYTHING that you are proud of doing today

EXERCISE 2.4

What I think you think about me

What do people think about me?

consequences

without
the thought

causes

Turn the belief to the opposite:



Find 3 specific examples where...

repeat 

1.

2.

3.





Who is judging whom?

Case study



Masimba had been feeling unwell for quite some weeks, with a bad cough. Three weeks ago, Masimba took a TB test and tested positive. At first, he seems to be okay and felt quite calm, but for the last few days he has been feeling that everyone is watching him and talking about him.

He gets the Combi (bus) to work and overhears two women talking about someone who is sick and has lost weight. He looks at his own body and is sure that he is losing weight and beginning to look thin. He wonders if they are talking about him.

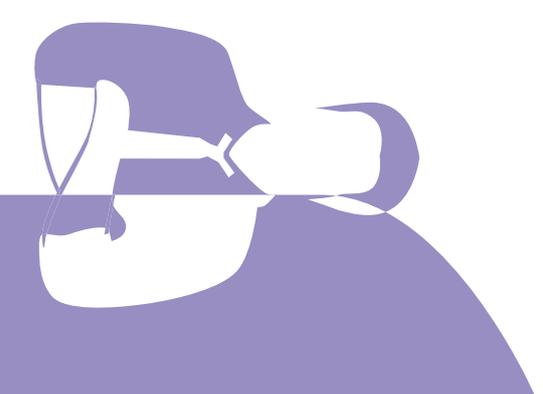
At work he notices a new poster about getting tested for TB. Masimba has not told anyone at work about testing positive for TB, but he immediately thinks someone has guessed and put the poster up as a well of telling others to be careful of him.

At lunch, he goes to join a table of co-workers and there is no space at the table. He immediately thinks it is because they don't want him near them, feels rejected he goes and sits on his own to eat his lunch.

His boss asks him how he is feeling, and he thinks she is asking him about having TB. He wonders if he looks sick. He starts to sweat, and the beginnings of a headache start. He thinks he should have stayed at home today.

His boss then tells him, he will be working on a new project for the next 4 weeks. Although this is a fantastic opportunity and one he has been looking forward to, now he thinks she is trying to get rid of him from her department.

The final straw happens when a co-worker brings him a cup of tea in a brand-new mug. Now he is sure that everyone is talking about him having TB. He feels miserable, isolated, alone, misunderstood and angry.



EXERCISE 2.7



Do you believe everything you think?

Example

I have TB and that means that... "I'm dirty"

consequences

- lack of urgency
- hopelessness
- want to hide
- shame
- anger
- isolation
- blame others

I AM DIRTY

causes

- fear of rejection
- TV / media
- low self esteem
- societal views

without the thought

- hopeful
- peaceful
- confident
- connected

Turn the belief to the opposite:

1. when I am with my children doing homework
I am NOT dirty

2. when I don't think you are judging me

3. when I am supporting others!

Find 3 specific examples where...
repeat I am not dirty

EXERCISE 2.7



Do you believe everything you think?

consequences

without the thought

causes

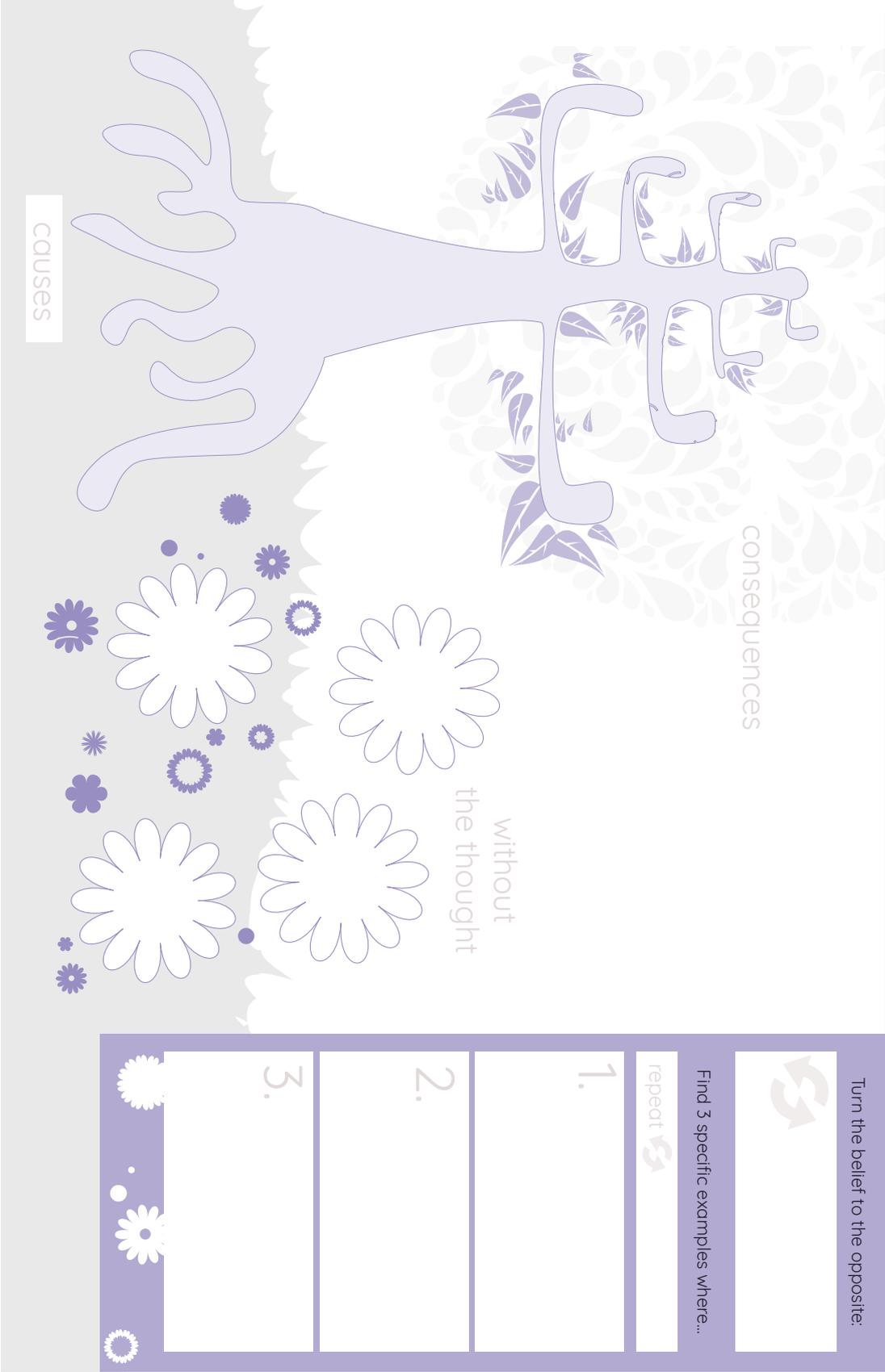
Turn the belief to the opposite:



Find 3 specific examples where...

repeat 

- 1.
- 2.
- 3.





Self-worth	high self-worth	shame	Self-stigma
	empowered	guilt	
	confident	hopelessness	
	strong self-agency	worthlessness	
	high self-esteem	secretive	
	open about TB diagnosis	hiding	
	comfortable in your skin	fearful to share information	
		distrustful	
		self-doubt	
		low self-confidence	



Adam is 37 years old with three children. His wife passed away six months ago, and he has started to have a prolonged cough and lose weight. One of his workmates has noticed he is not well and advises him to go to the clinic. Adam decides to go but he is worried he may have TB and maybe even be HIV positive. What will his family and friends say?

Adam goes to the clinic where a nurse does a TB test. The nurse tells him he has TB. This news upsets him – all he can think about is what people will say about him. The nurse tells him he must start treatment and gives him a number of instructions, but he hardly hears what she is saying. He takes the medicine she gives him and leaves the clinic in a confused state

After a few days, Adam returns to work. His colleague asks him, “What happened?” He says, “Nothing, I’m okay” and changes the topic of conversation. He feels like everyone is watching him and tries not to cough. When he is alone, he asks himself, “Who knows? How can I take treatment without people finding out? Will I lose my job? Are my children safe? Will they still be allowed go to School?”

Adam has an appointment to go back to the clinic. He is afraid to ask permission from his boss for more time off. He doesn’t know what to do.

Adapted from: STAMPP, CREATE, and International HIV/AIDS Alliance. (2009). *Understanding and challenging TB stigma - Toolkit for action*. 2009: ZAMBART Project, International HIV/AIDS Alliance.



EXERCISE 2.10



Where am I on the disclosure continuum?

Social Avoidance: Stay away from others so they do not have a chance to stigmatise me



Pros

Cons

Secrecy: Go out into the world doing your usual daily activities – but tell no one about my illness



Pros

Cons

Selective disclosure: Tell people about my illness who seem like they will understand



Pros

Cons

Indiscriminate disclosure: Hide it from no-one



Pros

Cons

Broadcast: Be proud and let everyone know



Pros

Cons

Classifications taken from: *On the Self-Stigma of Mental Illness: Stages, Disclosure, and Strategies for Change*, *Can J Psychiatry*. 2012 Aug; 57(8): 464–469 doi: 10.1177/070674371205700804.

EXERCISE 2.11



Three kinds of business

There are only three kinds of business in the universe: mine, yours, and God's / The Universe's. [God's being the Universe or any God you may have in your life].

Whose business is it if I am feeling happy or sad? **My business.**

Whose business is it if you are feeling happy or sad? **Your business.**

Whose business is the weather? **God's / The Universe's business.** (Anything that's out of my control, your control, and everyone else's control.)

Much of our stress comes from mentally living out of our own business. When I think, "You need to get a job, I want you to be happy, you should be kinder, you should be on time, you need to take better care of yourself," I am in your business. When I'm worried about earthquakes, floods, war, or when I will die, I am in God's / The Universe's business. If I am mentally in your business or in God's / The Universe's business, the effect is separation and loneliness. If you are living your life and I am mentally living your life, who is here living mine? We're both over there. Being mentally in your business keeps me from being present in my own. I am separate from myself, wondering why my life doesn't work. Of course I feel lonely and separated! No one else causes my loneliness. I do that.

Notice when you feel loneliness or separation. Are you mentally out of your business? If you are not sure, stop and ask yourself, "Mentally, whose business am I in?" Notice when you give uninvited advice either out loud or silently. Whose business are you in when you are giving unsolicited advice?

Adapted from: © 2016 Byron Katie International, Inc. All rights reserved. thework.com (slight adaptation made)

Whose business is it?
Check off your
responses below:

my business
your business
God's business

My height	_____	<input type="checkbox"/>	_____	<input type="checkbox"/>	_____	<input type="checkbox"/>
That I have TB	_____	<input type="checkbox"/>	_____	<input type="checkbox"/>	_____	<input type="checkbox"/>
Attending a concert	_____	<input type="checkbox"/>	_____	<input type="checkbox"/>	_____	<input type="checkbox"/>
Rush-hour traffic	_____	<input type="checkbox"/>	_____	<input type="checkbox"/>	_____	<input type="checkbox"/>
My mother's depression	_____	<input type="checkbox"/>	_____	<input type="checkbox"/>	_____	<input type="checkbox"/>
Your judgements of me	_____	<input type="checkbox"/>	_____	<input type="checkbox"/>	_____	<input type="checkbox"/>
My judgements of you	_____	<input type="checkbox"/>	_____	<input type="checkbox"/>	_____	<input type="checkbox"/>
The weather	_____	<input type="checkbox"/>	_____	<input type="checkbox"/>	_____	<input type="checkbox"/>
My boss's anger	_____	<input type="checkbox"/>	_____	<input type="checkbox"/>	_____	<input type="checkbox"/>
My body	_____	<input type="checkbox"/>	_____	<input type="checkbox"/>	_____	<input type="checkbox"/>

Other's judgements of us can only have power if we believe them. We have no control over judgements made against us, but we can choose whether we believe them or not or whether we apply meaning to those judgements.

EXERCISE 2.12

My agency, my power

Self-limiting beliefs

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____
7. _____
8. _____
9. _____
10. _____

Empowering beliefs

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____
7. _____
8. _____
9. _____
10. _____



Story of Struggle with MDR-TB: Xolelwa's story

I was diagnosed with MDR-TB in 2012. I got it from my twin sister who has been on MDR-TB treatment for the last 4 years and has now developed XDR-TB. She got the TB germs from her friend who had MDR-TB. The strange thing is that I never had any external symptoms of TB and neither did I ever feel sick. It was just because of the contact tracing of family members of my twin sister that my MDR-TB status could be confirmed."

"MDR-TB treatment is really a difficult one. We have to take so many big pills and injections for such a long time. On top of this, most of us have to suffer from severe side effects. It makes one feel very miserable and angry that why I got TB at all. TB develops negative emotions in us which increase our day to day problems. There is still some stigma around the disease in the community and neighbourhood. If you have TB people stay away from you and tell you on your face not to come near them."

"It is here that counsellors and voluntary health workers can help, as they did in my case. They visited me at home, gave me a lot of moral support, and encouraged me to continue with the treatment. I got a lot of support from my family too, especially my twin sister. My friends were also quite okay with me. My boyfriend, whom I met three years ago, also stood

by me. He is a social worker and also a cured TB survivor. Perhaps it was due to this that he did not let my TB affect our relationship."

"My message to all those with TB or DR-TB is to be brave and to accept it. Acceptance always makes things easier. It becomes difficult to fight the disease if you are depressed and harbour negative thoughts."



Adapted from: CNS interview with Xolelwa Joni in November 2013:
www.citizen-news.org/2013/11/story-of-struggle-of-mdr-tb-survivor.html



EXERCISE 3.1



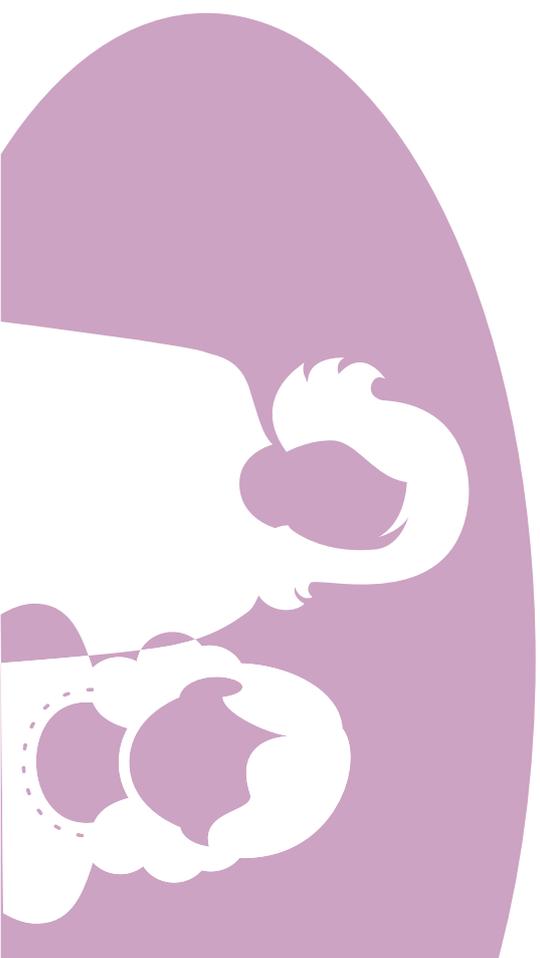
The many faces of DR-TB

Case study 2

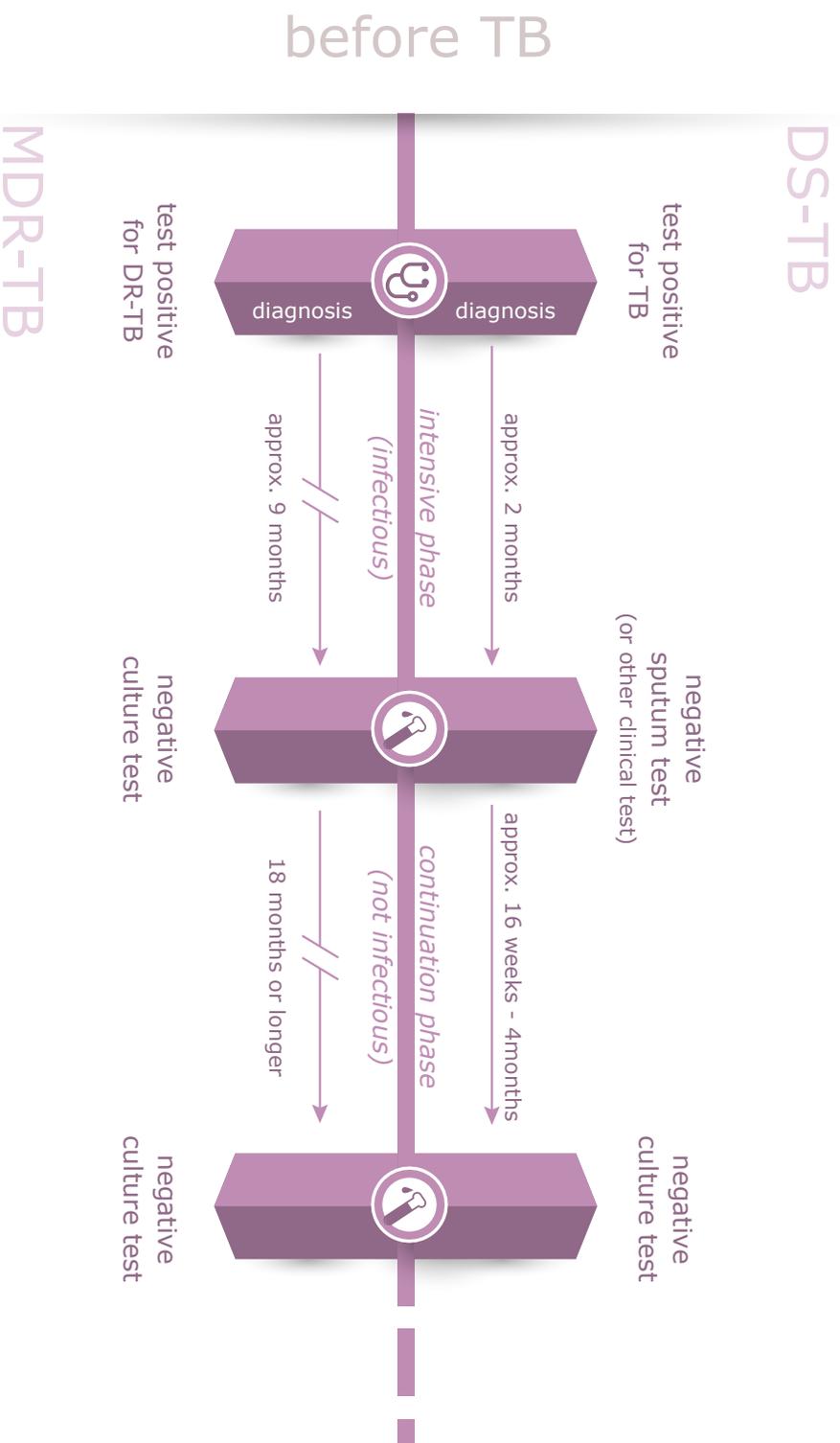
Rukmini's story: persistent low-grade fever and cough...

Rukmini, who was battling MDR-TB in Ahmedabad, Gujarat, India, and spoke with CNS in March 2013: "My family is very supportive of me despite the infectious nature of the disease" said Rukmini. But unfortunately, Rukmini's daughter contracted MDR-TB through her mother and has been on MDR-TB treatment in the same hospital since the last 6 months. The attending doctor, Dr Purvi told CNS that, "Direct MDR-TB transmission through contact is common. So, if a family member of such a MDR-TB patient has TB we test for MDR-TB in the beginning itself and if diagnosed put him/her directly on Category 4 treatment."

Although her daughter contracted MDR-TB, better late than never on infection control. Healthcare workers "have really counselled me well and I follow all their instructions regarding infection control methods at home - I spit in a spittoon given by the hospital, I bury my spit in mud, I keep my house very clean. I hope I will soon be able to go back to my work of selling fruits and not remain a financial burden on my loving husband.



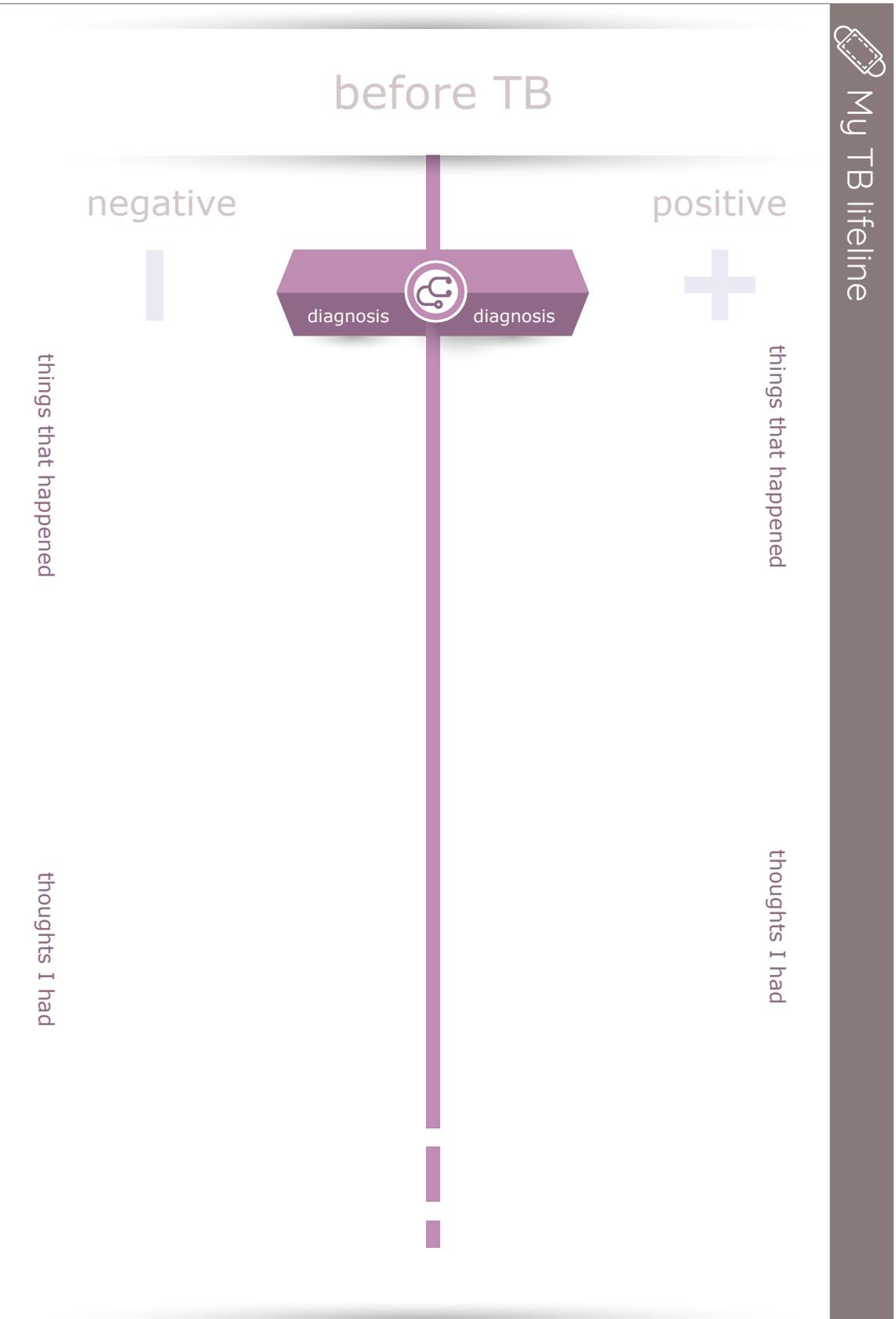
Adapted from: MDR-TB patient Rukmini's interview with CNS in March 2013:
<http://www.citizen-news.org/2013/08/persistent-low-grade-fever-and-cough.html>



EXERCISE 4.1



My TB lifeline



EXERCISE 4.2



TB quiz

Quiz

Answer the following questions by ticking either the true or false box

General

- 1 TB is an infectious, airborne disease that only affects the lungs. true false
- 2 TB is becoming harder to treat. true false
- 3 TB can attack any part of the body, e.g. lungs, glands, brain, spine, hip, intestines, genitals, eyes, etc true false
- 4 When the lungs are damaged by TB, a person coughs up sputum from the lungs and this produces TB droplets in the air. true false
- 5 Everyone who gets TB infection will become sick with TB disease. true false
- 6 Signs and symptoms of TB (especially TB of lungs) may include coughing, fever, sweating at night, loss of appetite, weight loss and feeling weak. true false

Prevention

- 17 Wearing masks is the best form of protection against TB. true false
- 18 Putting TB patients in isolated rooms is a good method for preventing TB. true false
- 19 Stopping the sharing of utensils is a good method for preventing TB. true false
- 20 It is important to get tested if you have a prolonged cough or cough up blood. true false
- 21 If you are coughing or sneezing you should cover your nose and mouth. true false
- 22 People living with HIV who don't have active TB disease but have latent TB infection, should take preventive therapy. true false

Transmission

- 7 You get TB by breathing in germs in the air from a person with TB who is coughing. true false
- 8 All people who are coughing are infectious – they can spread TB to others. true false
- 9 You can get TB through shaking hands, touching or kissing someone who has TB. true false
- 10 You will 100% get TB through staying in the same house with someone who has TB. true false
- 11 You can still transmit TB to other people despite being cured true false
- 12 Health workers will 100% get TB because of frequent exposure to patients with infectious TB disease. true false

Testing / treatment

- 23 All forms of TB are diagnosed by examining the patient's sputum. true false
- 24 A person cannot take TB treatment at the same time as taking ARVs. true false
- 25 You can be cured of all forms of TB if you take treatment consistently for six or eight months. true false
- 26 The side effects of TB treatment are ... true false
- 27 During TB treatment eat well, avoid alcohol and tobacco, and avoid stress. true false

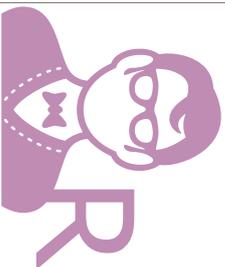
Myths

- 13 Having sex with a virgin cures TB. true false
- 14 Women have more TB germs. They are the ones who give men TB. true false
- 15 There are two types of TB – old TB and new (HIV-linked) TB. true false
- 16 People whose families have had TB (e.g. grandfather) are more at risk of getting TB. true false

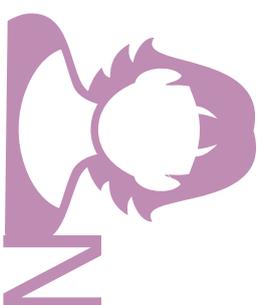


Rights and the patient with TB

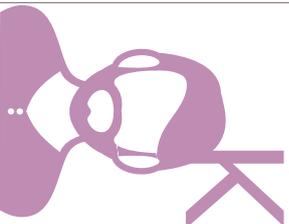
Case studies



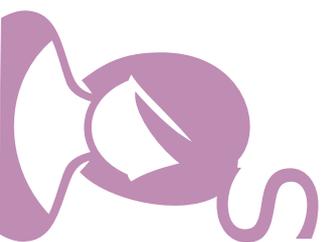
Robert is a married man with three children. He and his family were chased out of his house when his landlord discovered that he had TB. The landlord said he didn't want Robert to infect other people and that it would be bad for his business.



Natalie has been on TB treatment for two weeks and has not been responding well. She is very sick. Her family calls a meeting and decides that she should stop taking the drugs and go to her grandmother's house in the village where she can rest and recover.



Kenneth has had TB for the last three months and is responding to treatment well. He stays with his family and while he is there, the family starts planning the wedding for his youngest sister. Kenneth asks to help with the wedding arrangements, but his father tells him, "People like you don't need to be involved in these things".

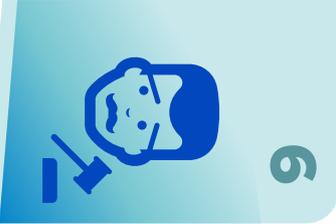
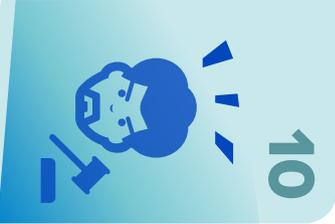
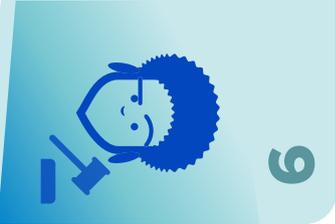
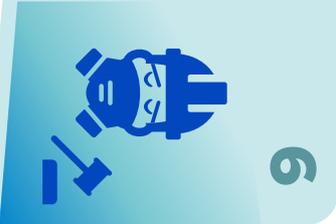
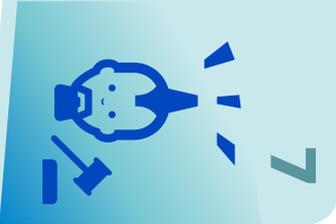
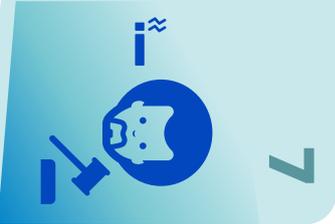


Selina is a young woman who is living with her grandmother. She was diagnosed with TB a few months ago and has been responding well to treatment. Recently she met a young man whom she really likes and hopes to marry one day. However, her grandmother has told her that she cannot be in a relationship – she must wait until her TB treatment is finished and she is sure that she is well.

STIGMA CARD (BACK)



STIGMA CARDS (FRONT)

<p>Blame B5</p>  <p>6</p> <p>If X had not been drinking or drugging X would not have gotten TB.</p>	<p>Blame B1</p>  <p>10</p> <p>If X had taken better care of myself, X would not have developed TB disease.</p>
<p>Blame B6</p>  <p>5</p> <p>If X had not been detained, X would not have gotten TB.</p>	<p>Blame B2</p>  <p>9</p> <p>If X had taken my TB treatment as instructed, X wouldn't have developed drug-resistant TB.</p>
<p>Blame B7</p>  <p>6</p> <p>If X had worn my respirator at work, X would not have gotten TB.</p>	<p>Blame B3</p>  <p>8</p> <p>If X had taken my ART and IPT as instructed, X would not have developed TB disease.</p>
<p>Blame B8</p>  <p>7</p> <p>If X had not spent time in certain places, X would not have gotten TB.</p>	<p>Blame B4</p>  <p>7</p> <p>If X had not smoked, X would not have gotten TB.</p>

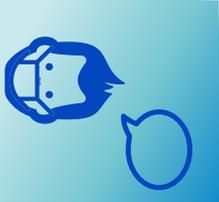
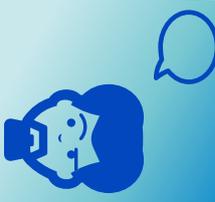
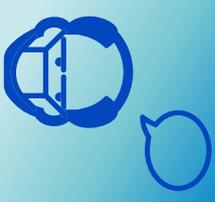


STIGMA CARDS (FRONT)

<p>Guilt g1 </p> <p>6</p> <p>I feel bad for exposing my loved ones to TB.</p>	<p>Blame b9 </p> <p>8</p> <p>If X had avoided certain people, X would not have TB.</p>
<p>Guilt g2 </p> <p>5</p> <p>I feel upset when TB disease makes it hard for me to care for my family.</p>	<p>Stereotype s1 </p> <p>9</p> <p>X is less careful than others because X developed TB disease.</p>
<p>Guilt g3 </p> <p>4</p> <p>Caring for me is a financial burden on my family.</p>	<p>Stereotype s2 </p> <p>8</p> <p>X is not clean because X developed TB disease.</p>
<p>Lie l1 </p> <p>5</p> <p>I can never measure up to ordinary people because I developed TB disease.</p>	<p>Stereotype s3 </p> <p>7</p> <p>X's body is inferior to others because X developed TB disease.</p>



STIGMA CARDS (FRONT)

<p>Lie L6</p>  <p>4</p> <p>TB patients cannot be trusted to practice cough hygiene, they should be isolated.</p>	<p>Lie L2</p>  <p>6</p> <p>The disease is a sign of weakness.</p>
<p>STIGMATIZED</p> <p>FIRST PLAYER</p> 	<p>Lie L3</p>  <p>7</p> <p>TB disease is something that happens to careless people.</p>
<p>Lie L4</p>  <p>6</p> <p>It is quite normal to shun people with TB because TB is air-borne.</p>	<p>Lie L5</p>  <p>5</p> <p>TB patients cannot be trusted to take their medicines alone.</p>

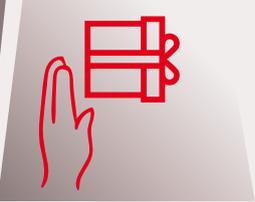
FIRST PLAYER CARD (FRONT)



HELP CARD (BACK)

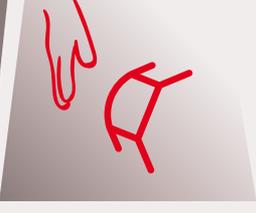
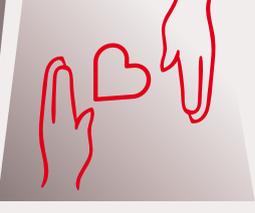


HELP CARD (FRONT)

<p>3</p>  <p>Love</p> <p>Walk alongside me in whatever journey I'm on without trying to fix me.</p> <p>Icons: thumbs up, thumbs down, speech bubble, two people</p>	<p>5</p>  <p>Love</p> <p>When I forgive myself, I set myself free.</p> <p>Icons: thumbs up, thumbs down, speech bubble, two people</p>
<p>2</p>  <p>Love</p> <p>Humans are all beautiful in our imperfection.</p> <p>Icons: thumbs up, thumbs down, speech bubble, two people</p>	<p>6</p>  <p>Love</p> <p>Forgiveness is a gift we all can give.</p> <p>Icons: thumbs up, thumbs down, speech bubble, two people</p>
<p>1</p>  <p>Love</p> <p>Every life matters infinitely.</p> <p>Icons: thumbs up, thumbs down, speech bubble, two people</p>	<p>5</p>  <p>Love</p> <p>I am conquering my illness. I am defeating it steadily each day.</p> <p>Icons: thumbs up, thumbs down, speech bubble, two people</p>
<p>2</p>  <p>Love</p> <p>There is a crack in everything. That's how the light gets through.</p> <p>Icons: thumbs up, thumbs down, speech bubble, two people</p>	<p>4</p>  <p>Love</p> <p>Walk alongside me in whatever journey I'm on without judging me.</p> <p>Icons: thumbs up, thumbs down, speech bubble, two people</p>



HELP CARD (FRONT)

<p>3</p>  <p>Love</p> <p>L117</p> <p>No one can make you feel inadequate without your consent.</p> 	<p>3</p>  <p>Love</p> <p>L113</p> <p>To be creative is to be come home to ourselves.</p> 
<p>2</p>  <p>Love</p> <p>L118</p> <p>Allow people to make different decisions and to have different experiences than you would.</p> 	<p>4</p>  <p>Love</p> <p>L114</p> <p>Love weaves beauty out of pain.</p> 
<p>1</p>  <p>Love</p> <p>L119</p> <p>Release control and we honour differences.</p> 	<p>5</p>  <p>Love</p> <p>L115</p> <p>What you see on the outside is not all I am on the inside.</p> 
<p>2</p>  <p>Love</p> <p>L120</p> <p>Treating yourself with care, consideration, kindness, compassion and love is part of recovering from a health problem.</p> 	<p>4</p>  <p>Love</p> <p>L116</p> <p>Solidarity is the tenderness of the people.</p> 



HELP CARD (FRONT)

<p>1</p>  <p>Love L25</p> <p>I will feel relief once my strength returns.</p> 	<p>3</p>  <p>Love L21</p> <p>If your compassion does not include yourself, it is incomplete.</p> 
<p>2</p>  <p>Love L26</p> <p>When I get over TB disease, there is a lot ahead of me.</p> 	<p>4</p>  <p>Love L22</p> <p>The person who is more deserving of your love than yourself can not be found.</p> 
<p>10</p>  <p>Justice J1</p> <p>We have a right to health care: equitable access, without discrimination, to TB education, prevention and care according to established standards of care, including the needs of PW/MTB with MDR-TB and HIV co-infection.</p> 	<p>3</p>  <p>Love L23</p> <p>Things will go back to normal once TB treatment is done.</p> 
<p>8</p>  <p>Justice J2</p> <p>We deserve to be treated with dignity: my TB services must be provided in a respectful environment, without stigma, and with moral support from the community.</p> 	<p>2</p>  <p>Love L24</p> <p>I have plans for my life after TB treatment is over.</p> 



HELP CARD (FRONT)

<p>3</p>  <p>We have the right to organize: to participate as stakeholders in policies and programs and establish TB survivor platforms.</p> <p>J7 Justice</p> 	<p>2</p>  <p>We have a right to Information: on all aspects of TB, including prognosis, costs, side effects, and other consequences, and to share experiences with peers.</p> <p>J3 Justice</p> 
<p>7</p>  <p>We have the right to protection from discrimination: my job security should not be threatened while I am recovering.</p> <p>J8 Justice</p> 	<p>4</p>  <p>We have choices: to have a second opinion, access to medical records, accept or refuse medical interventions and to take part- or not-in research.</p> <p>J4 Justice</p> 
<p>5</p>  <p>We deserve sustenance: nutrition security or food supplements if needed.</p> <p>J9 Justice</p> 	<p>2</p>  <p>My right to privacy must be respected: uphold patient-provider confidentiality laws, in contact investigation.</p> <p>J5 Justice</p> 
<p>6</p>  <p>We have a right to life: States must adopt measures in law and policy to protect the lives of people with TB, including ensuring access to testing and life saving treatment.</p> <p>J10 Justice</p> 	<p>4</p>  <p>We deserve justice: we have the right to complain, to appeal and to be heard promptly and fairly.</p> <p>J6 Justice</p> 



VICTORY CARD (FRONT)

Hurray!
You are the most knowledgeable player

VICTORY CARD

Yes!
You are the most empathetic player

VICTORY CARD

Wow!
You are the most righteous player

VICTORY CARD

HELP CARD (FRONT)

6

We have a right to medicine: States have a core obligation to provide essential medicine on the WHO Model List of Essential Medicines-including 1st/2nd-line anti-TB drugs, bedaquiline and delamanid

J11 Justice

7

We have a right to be free from discrimination: People with TB must be protected by law against discrimination in both the public and private spheres, including employment, education, housing, health care settings, etc.

J12 Justice

5

We have the right to be free from torture and other cruel, inhuman or degrading treatment or punishment: Law and policy must ensure people in prisons and other detention centers are provided clean air, TB testing and treatment services

J13 Justice

4

We have the right to liberty and security of person: Law and policy must establish clear protections against involuntary detention or isolation of people with TB, except under exceptional circumstances, as a last resort, or when a person is known to be or highly likely to be contagious but refuses treatment or testing and all reasonable measures have been unsuccessful-then the least restrictive possible measure must be used.

J14 Justice





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